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Ethics of Research with Human Subjects

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Description

Prepared for presentation at the Research Ethics Institute, North Carolina State University, June 2001, this synopsis of a presentation by Dr. Kenneth D. Pimple includes three dialogue-based case studies with a commentary featuring Polly Wells, who is either the owner of a small diner, a newspaper columnist, or a sociologist in this series of cases. Each case explores the different professional obligations Polly faces when she witnesses a case of police violence.

Body

My charge

I was invited to make a presentation on “Ethics of Research with Human Subjects,” and to cover the following topics:

- Risks and benefits to people participating in qualitative research.
- Researcher obligations to people being studied.
- Researcher obligations to a school, neighborhood, or community where people are being studied.
- Researcher obligations to her/his home institution (NCSU). □ Legal obligation to report child abuse, etc.

- Anonymity, confidentiality, and privacy.

I was also told that the Institute would have a strong pedagogical slant and asked to bear this in mind as I prepared my presentation.

I offered these background readings:

Gunsalus, C. K. 1998. "[How to Blow the Whistle and Still Have a Career Afterwards.](#)" *Science and Engineering Ethics* 4:51-64.

I think every researcher should read this, and every mentor should discuss it with her or his students.

National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. 1979. [The Belmont Report](#).

The foundational document for the responsible conduct of research with human subjects in the United States. It is short, to the point, and profound; everyone who does research with human subjects should read it.

Pimple, Kenneth D. 2001. "[The Six Domains of Research Ethics: A Heuristic Framework for the Responsible Conduct of Research](#)" *Science and Engineering Ethics*. 8:191-205.

I also offered several items on teaching research ethics:

Pimple, Kenneth D. 1999. "[A Short List of Useful Resources for Teaching Research Ethics](#)"

Pimple, Kenneth D. 2001. "[Using Short Writing Assignments in Teaching Research Ethics](#)"

Pimple, Kenneth D. 2001. "[Using Small Group Assignments in Teaching Research Ethics](#)"

Poll

To prepare for my session (and to model a pedagogical tactic), I sent an e-mail message to participants in the 2001 NCSU Research Ethics Institute on 25 May 2001 asking 3 questions; 15 of the 19 participants (79%) responded. Here is a summary and synthesis of the responses.

(1a) Do you do research with human subjects?

Yes	7
No	8
No response	4

(1b) If so, please briefly describe the kind of research you do and the kinds of interactions you have with human subjects (e.g., telephone survey, participant observation, structured face-to face interviews, study of existing data, etc.).

Mostly qualitative research, including surveys via e-mail, face-to-face surveys, telephone surveys, structured and semi-structured interviews, participant observation, and study of existing data.

(2) What is your level of comfort or familiarity with the human subjects review process at NCSU? That is, do you have a lot to learn, can you negotiate the system with ease and answer all of your students' and colleagues' questions, or are you somewhere in between?

Low	7
Medium	8
High	4

Does research with human subjects

Level of comfort	Yes	No
Low	1	6
Medium	4	1
High	2	1

(3) What one thing (insight, teaching technique, bit of knowledge, skill) do you hope to gain from this session?

Better understanding of regulations (5) With regard to marginalized populations (1)

With regard to research undertaken by students (2)

With regard to survey research (1)

With regard to qualitative research (1)

Ideas for teaching (5)

Deeper understanding, new insights (5)

Whether, and if so under what circumstances, we have a moral obligation to become human subjects

Basic Regulatory Issues

With this poll as a background, it seemed evident that my work was cut out for me. How could I meet the needs of this diverse group, covering a topic as broad as “ethical issues in human subjects research,” and in only one hour?

To help the participants with a low level of comfort or familiarity with the research project, I asked the Institute organizers to adapt and distribute a short paper I had prepared for use at Indiana University: “[The Least You Need to Know about the Rules Governing Human Subjects Research](#).” Then I prepared a case study for discussion, with the hope that the discussion would uncover the fundamental ethical issues involved in non-biomedical (non-invasive) research with human subjects.

Case Study for Discussion

One day in late April or early May of 2001, riders on a city bus at a bus stop saw a police car, lights flashing, on the street corner. Police officers were questioning a young man, in his late teens or early twenties, who had apparently been driving an old, beat-up car.

Two middle aged or elderly male bus riders who appeared to be poor, perhaps homeless, possibly moderately intoxicated, started discussing the situation loudly. One of them claimed that the Bloomington police routinely harassed him and other poor people, and that the police in Bloomington were worse than the police in any of the many other cities in which he had lived. To this point, the case accurately represents an actual experience I had. The rest of the case is fictional. A third passenger, obviously of higher financial standing than the two men, joins the conversation.

WELLS: Is it really that bad? The two men appraise her; she extends her hand. I'm Polly Wells. They shake hands; the two men relax at her friendly manner.

BLACK: I'm Tom Black. He's Isaac Katzenberger.

WELLS: Pleased to meet you. Is it really that bad? I've always thought the Bloomington

BLACK: Snorts. You just don't know. The cops in this town hate poor people. Just walking down the street, they stop you every time. Frisk you. Ask you, you drunk? On drugs? Steal anything lately?

WELLS: Listening respectfully and with evident sympathy. Hmm.

BLACK: Never hassle rich folks, folks got nice clothes. WELLS: What's the worst they do?

BLACK: Rough you up. You been frisked? It can hurt. Throw you to the ground, twist your arms. Take you to jail when you ain't done nothing.

WELLS: That's bad.

BLACK: Worse than Chicago. Worse than Indy. They got nothing better to do than hassle poor folks.

The conversation continues for several minutes; Katzenberger never enters the conversation, but nods approvingly at everything Black says. The two men debark near a homeless shelter; Wells stays on the bus. Polly Wells is a completely fictional character. I should note that the conversation I overheard on the bus is the only indication I have that the Bloomington police harass poor people. I can neither support nor deny the truth or accuracy of their comments.

Case 1: Polly Wells is the owner of a small diner. In the next few days she will comment on the conversation to a few friends, then it will fade from her memory.

Case 2: Polly Wells is a columnist for the local newspaper. When she gets home she writes a column about the conversation; it is published two days later.

Case 3: Polly Wells is a sociologist working on a research project concerning relationships between the Bloomington police and the poor. When she gets home she takes notes on the conversation, capturing as accurately as she is able the actual words spoken. She later quotes her notes in a scholarly paper published in a highly esteemed journal.

Questions for discussion.

1. What practical differences are there between cases 1, 2, and 3? What effects are her actions likely to have on Black and Katzenberger in each case? On anyone else? (Who else?)
2. What moral differences are there between cases 1, 2, and 3? What legal differences are there?

My answers:

Practical differences.

Case 1: Wells owns a small diner.

1. There is not likely to be any effect on Black and Katzenberger or anyone else.
2. At a stretch, we might suppose that Wells and a few of her friends will be more sensitive to the issue of relationships between the police and the poor. (There are many possible outcomes; for example, Wells might run for Mayor, be elected, and clean up the police department. This is not likely, however, and consideration of every possible outcome is beyond the scope of this paper.)

Case 2: Wells is a columnist.

1. If Wells uses their names in the column, Black and Katzenberger will almost certainly hear about the column and will likely read it.
2. Whether their names are used or not, Black and Katzenberger might learn of the column, and if they do, they will almost certainly recognize themselves as the source. They could be pleased to get the attention; they could be annoyed or angry and feel that they were duped.
3. The police department will almost certainly denounce the column, especially if Wells did not interview any police sources or attempt to verify or falsify Black's statements.
4. There will probably be some conversation around town about the column; it might lead to further investigations, which might (in turn) lead to some changes.
5. There may be negative consequences for Wells and the newspaper because of her unprofessional conduct (see next part).

Case 3: Wells is a sociologist.

1. Black and Katzenberger will probably never know that the conversation was published. In fact, no one in Bloomington outside of Wells' close circle of friends and colleagues is ever likely to learn about it.
2. The publication will advance her career to some degree.
3. The publication will add to the pool of knowledge on relationships between the police and the homeless, which could lead to changes in policies. I cannot estimate the likelihood of this, but I feel certain that this conversation would play only a small role in her paper, which would play only a small role in any policy changes.
4. There may be negative consequences for Wells and her university because of her unethical conduct (see next part).

Moral differences.

Case 1: Wells owns a small diner.

1. She did nothing wrong or questionable.

Case 2: Wells is a columnist.

1. She had an ethical obligation to identify herself to the men as a columnist and get their permission to publish the column. Failing to do so violated their moral (and perhaps legal) right to privacy. Publishing a conversation in a newspaper is very different from repeating it to a few friends:

1.1. The newspaper column reaches many more people (probably by several orders of magnitude).

1.2. Most of the people who read the column live in the same community as Black and Katzenberger; some people who know them are likely to read it.

1.3. Wells has no control over who it reaches; in Case 1 she can be reasonably sure whether her friends might start a vendetta against Black and Katzenberger or against the police.

1.4. It creates a permanent record.

2. If she had any inkling that she would publish the results of the conversation, she should have identified herself as a columnist and gotten permission from the two men to write about the conversation.

2.1. If she only realized after the conversation that it would make a good column, she should have made a reasonable effort to find the men and get their permission to publish. After all, she knows where they are staying and could easily call or visit the homeless shelter.

2.2. If she made a reasonable effort to reach them but was unsuccessful, it may have been acceptable to publish the conversation without using the men's names.

Case 3: Wells is a sociologist.

1. She had an ethical obligation to identify herself to the men as a researcher and get their informed consent to use the conversation as data for her research. Failing to do so violated their moral (and perhaps legal) right to privacy. Publishing a conversation in a scholarly journal is different from repeating it to a few friends or publishing it in a newspaper:

1.1. The journal article reaches more people than the conversation; it may reach more or fewer people than the newspaper column.

1.2. Most of the people who read the journal article will not be in the same community, and it is unlikely that many (if any) of the readers will be able to identify Black and Katzenberger.

1.3. It is highly unlikely that the journal article will motivate anyone to start a vendetta against Black and Katzenberger or the police.

1.4. It creates a more permanent record than a newspaper article.

2. She also violated federal and university regulations concerning human subjects research.

3. Getting consent to use data in a research study is different in at least two ways from getting permission to publish information in a newspaper (leaving the regulatory/legal differences aside):

3.1. Black and Katzenberger are almost certainly familiar with newspapers and probably have a fairly good sense of what it means to be interviewed by a newspaper columnist, including the potential consequences to them. They may decline to be quoted out of fear of reprisals from the police. They are highly unlikely to be familiar with sociological research. Wells has a moral (as well as regulatory) obligation to respect their autonomy and protect their rights by explaining her study to them in some detail so they can make a reasonable judgment about whether they want to take part.

3.2. The press (newspapers) is explicitly protected by the Constitution. Scholarly journals are not. This does not mean that scholars do not enjoy the right to free speech, but it does suggest that their right to free speech may be modified or curtailed in certain ways.

4. In Case 1 and Case 2, Wells and the people who learn of the conversation from her are all or almost all part of the same community. Wells, the men, and the auditors/readers have a similar level of identification with each other. In Case 3, Wells is more removed from the community, I do not mean to suggest that scholars are estranged from the towns in which they live; but town-gown issues are well known and not always trivial. and the readers of his article are even more seriously removed. For these reasons (and others), Wells' behavior in Case 3 treats the men

more as objects, as data points, than as autonomous human beings; she uses them, treating them as a means only and not as ends in themselves. In Case 1, Wells treats the men as ends in themselves; in Case 2, she uses them to some degree, but not (in my opinion) to the same degree as in Case 3.

Notes

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